

America's Health Insurance Plans

# Collection and Use of Race and Ethnicity Data for Quality Improvement

2006 AHIP-RWJF Survey of Health Insurance Plans



**Issue Brief** 

Funding Provided by the Robert Wood Johnson Foundation

#### **Acknowledgements**

America's Health Insurance Plans thanks the Robert Wood Johnson Foundation for their funding support that made this survey possible under grant #56407.

The following individuals contributed to the writing and editing of this publication:

Julie Gazmararian, PhD, MPH, consultant

**AHIP Staff** 

Rita Carreón

Carmella Bocchino

Barbara Lardy

German Veselovskiy

Susan Pisano

If you have any questions about this publication, please contact:

Rita Carreón, Senior Manager, Clinical Strategies America's Health Insurance Plans 601 Pennsylvania Avenue, NW South Building, Suite 500 Washington, DC 20004

Phone: 202.778.3239 Fax: 202.778.3287 rcarreon@ahip.org

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#### **BACKGROUND**

The demographic landscape in the United States has changed significantly. According to U.S. Census 2000, Hispanics/Latinos are currently the largest minority group residing in the United States, and are the fastest growing population in the country. By 2050, Hispanics/Latinos will make up nearly 25% of the U.S. population, and minorities in general are predicted to represent half of the total population.1

Studies have shown that Americans receive health care services that are in sync with the latest scientific evidence only half of the time.<sup>2</sup> It is also evident that health disparities exist across most racial and ethnic groups in the U.S., with minorities reporting higher rates of disease, morbidity, and mortality, regardless of access to health insurance.3 Disparities also exist in access to quality health care services, and have been tied to poorer clinical outcomes and disease prognosis.4 In addition to racial and ethnicity, language barriers also affect access to quality health care throughout the course of disease treatment.5 As the demographic make-up of the U.S. continues to shift, the burden of race and ethnic disparities and their root causes are becoming more important. Through data collection, health care organizations have an opportunity to identify disparities in health and health care and implement innovative solutions to close the gaps in care.

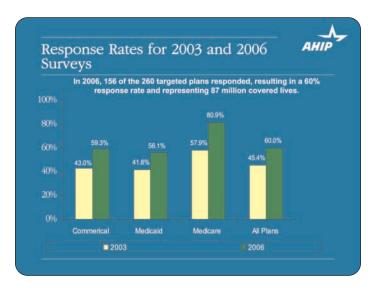
There is widespread agreement that valid and reliable race and ethnicity data are fundamental building blocks to identifying disparities, to developing programs that close the gaps in care, and to ensuring a higher standard of care.6

Presently there is no consistent, widely used method for collecting race and ethnicity information. One potential approach calls for health insurance companies to collect this information from their enrollees in addition to other standard demographics, and to use this information to identify disparities in health care and improve overall quality of care for their enrollees. With the addition of race and ethnicity information, health insurance companies which already routinely monitor quality measures are in a position to study the same measures across minority groups.7

In 2003/04, American's Health Insurance Plans (AHIP) collaborated with the Robert Wood Johnson Foundation (RWJF) to survey member and non-member plans about the extent to which they collect and use data on the race, ethnicity, and primary language of their enrollees to improve quality of care. 8.9 The 2003 survey was the first time that such practices were measured across the health plan industry.

In 2006, AHIP conducted a survey to the assessment conducted in 2003/04. The purpose of this survey was to: (1) assess any trends or major differences from the 2003 survey; (2) assess the extent to which health insurance plans collect and use race and ethnicity data (including primary language); and (3) highlight barriers to the collection of these data. In 2006, 156 of the 260 targeted plans responded, resulting in a 60% response rate (see Figure 1). When weighted by enrollment, the responding health insurance plans represent 87 million covered lives. Response rates varied by product with Medicare plan types having the highest response rate followed by Commercial and Medicaid plan types.

The 2006 AHIP-RWJF survey also offers an opportunity for AHIP, its member companies, and RWJF to expand on the issues identified in the initial survey and continue to learn from the experiences and practices of health insurance plans. This work is part of a broader commitment by AHIP and its member plans to address disparities in health and advance access to high quality, and affordable health care.



Response Rates for 2003 and 2006 Surveys

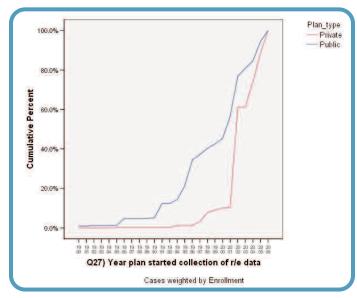
\*Data is unweighted

#### **COLLECTING THE DATA: KEY ANALYTICAL POINTS**

#### Collection of Data on Race and Ethnicity to Help Reduce Disparities

Over the past three years, health insurance plans have made significant strides in collecting race and ethnicity data of enrollees to help reduce disparities. As is evident from Figure 2 (weighted by enrollment), the 2006 AHIP-RWJF survey found a clear upward trend in the collection of data on race and ethnicity by health insurance plans. Collection of race and ethnicity data by plans that responded to the survey was almost non-existent during the 1980s, which was followed by a period of a slow, but steady increase between 1990 and 2001. Since 2001 there has been an explosive growth in such data collection. By the second quarter of 2006, the number of health insurance plans (weighted by enrollment) that collect such information grew approximately five times since 2001.

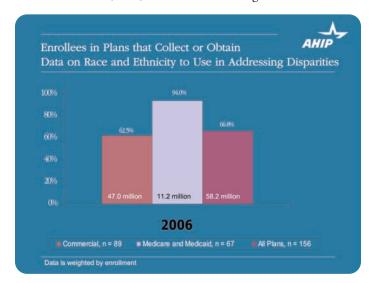
While several studies and reports, such as the Institute of Medicine's *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* report, may have largely influenced the collection of race and ethnicity data, health insurance plans understand that collecting valid and reliable race and ethnicity data of their enrollees is an important first step towards identifying disparities and creating workable solutions to close the gaps in care.



**Figure 2**Health Plans Have Increased their Data Collection Relative to Addressing Disparities by 500 percent since 2001

Note: Description of methodology can be found following the Methodology summary on page 8.

In 2006, 67% of the enrollees are covered by health insurance plans that collect or obtain race and ethnicity data. This proportion represented by respondents varied by Commercial (63%), Medicaid and Medicare plans (94%) (see Figure 3). Medicaid and Medicare plans receive data on race and ethnicity of their enrollees from federal and state agencies, such as the Centers for Medicare & Medicaid Services (CMS) and state Medicaid agencies.



**Figure 3**Enrollees in Plans that Collect or Obtain Data on Race and Ethnicity to Use in Addressing Disparities

## Using Data to Help Identify Health Disparities and Improve Quality

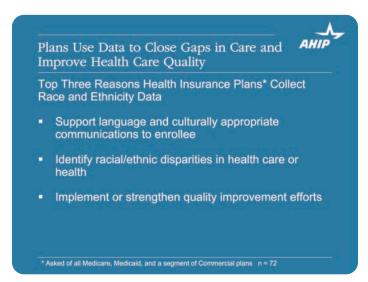
In 2006, health insurance plans were asked to identify their major reasons for collecting race and ethnicity data. The three most common reasons\* included to: support language and culturally appropriate communications to enrollees, identify racial and ethnic disparities in health care, and implement or strengthen quality improvement efforts.

In addition, a segment of Commercial plans presented with an expanded choice of options also listed the following five major reasons for collecting data on race and ethnicity from their enrollees:

- Conduct research
- ▶ Identify enrollees with risk factors for certain conditions
- ▶ Support language and culturally appropriate communication to enrollees
- Assess variation in quality measures by race and ethnic groups
- Strengthen quality improvement initiatives

These reasons are similar to the 2003 survey, but differ slightly in order of ranking.

\*The three most common reasons reflect all Medicaid and Medicare plans, and a segment of Commercial plans.



**Figure 4**Top Three Reason Plans Collect Race and Ethnicity Data of Enrollees

Forty-two percent of plans have identified health or health care disparities among their enrollees. This proportion, represented by respondents, is lower for Commercial and Medicare plans (37% and 39%, respectively) compared to Medicaid plans at 48%. The most common types of disparities identified by health insurance plans include<sup>†</sup>:

- Differences in treatment of one or more chronic conditions (86.8%)
- Lack of medication adherence (49.7%)
- Differences in prevalence of one or more chronic conditions (49.2%)

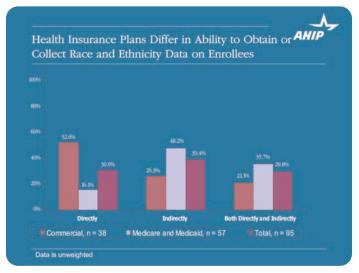
Health insurance plans, which routinely develop quality improvement initiatives for their enrollees, are consistently looking for ways to improve access, affordability, and quality of care for all of their members. With the collection of race, ethnicity, and primary language data, plans strengthen quality improvement programs and develop targeted interventions to address the specific needs of culturally diverse populations. They are also able to study the causes, measure their progress in reducing disparities, and allocate resources accordingly.

#### Most Common Methods Used

In 2006, responding plans used a variety of direct strategies for collecting data on the race and ethnicity of their enrollees. Across all plans that collect these data, the most common strategies included collecting data from enrollees *after* enrollment, collecting these data when an enrollee participates in a special program, or when self-identified by the enrollee *during* enrollment.

<sup>†</sup>Percentage reflects the percent of enrollees covered by plans that identified the types of disparities

Among the 95 plans that indicated they currently collect race and ethnicity data on their enrollees, 31% of health insurance plans collect race and ethnicity data directly from the individual, 39% indirectly and 30% of health insurance plans use both direct and indirect methods. Collection of race and ethnicity data varied by type of product with Commercial plans more likely to collect the information directly from enrollees, while Medicaid and Medicare use both indirect and direct methods (see Figure 5).

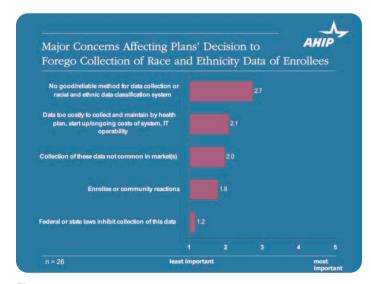


**Figure 5**Health Insurance Plans Differ in Ability to Obtain or Collect Race and Ethnicity Data on Enrollees

#### Despite Strides, Challenges Remain in Data Collection

Almost 30 million enrollees represented by our survey are in plans that do not collect race and ethnicity data (33% of 87 million enrollees represented in the total sample). Of the 61 plans that indicated they do not collect race and ethnicity data on their enrollees, 41% of Commercial plans, 50% of Medicaid and 50% of Medicare plans indicated that they have concerns that affected their decision to collect this information.

When these 61 plans were asked to rank the top five concerns that may have affected their plan's decision not to collect race and ethnicity data on their enrollees, 26 plans responded. These respondents indicated that their major concern was that there was no good or reliable method for data collection. Other reasons were also suggested as shown in Figure 6.



**Figure 6**Major Concerns Affecting Plans' Decision to Forego Collection of Race and Ethnicity Data on Enrollees

The lack of good or reliable method for data collection continues to be a major concern among respondents that do <u>not</u> collect these data.

Health insurance plans are also concerned with how enrollees will react to the collection of these data. These concerns were validated through focus groups conducted by AHIP with African Americans and Hispanics/Latinos in 2005 and in a RWJF-funded *Public Opinions Strategies* consumer survey. The results from the consumer survey stated that 50% of respondents did not find it acceptable for an HMO or health insurance company to collect race and ethnic origin information.<sup>10</sup> However, the survey participants and AHIP's focus groups exhibit a willingness to answer questions about race, ethnicity, and primary language if they were asked on a volunteer basis, and if the reasons for data collection were fully explained (e.g., to ensure that all American's equal access to high quality care).

As in 2003, another major concern is health insurance plans' misperception that federal and state laws inhibit the collection of race and ethnicity data. AHIP's research and several reports confirm that it is legal to collect these data for quality improvement efforts. According to a recent report, federal laws prohibiting discrimination on racial or ethnic grounds, and specifically the Title VI of the 1964 Civil Rights Act, contain no legal liability for health care providers who collect race and ethnicity data on their patients as part of an overall quality improvement effort. The report, funded by the

RWJF, stresses that such practices are consistent with the regulations and comply with the law, thus advancing the purpose of Title VI.<sup>11</sup>

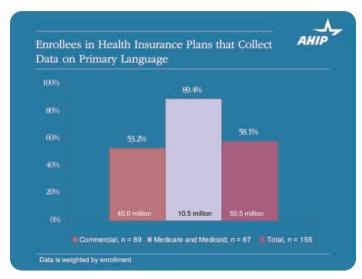
Six states (California, Maryland, New Hampshire, New Jersey, New York, and Pennsylvania) have laws or regulations restricting health insurance plans from collecting data on race and ethnicity in certain circumstances. However, those state laws and regulations apply only to one aspect of the process, namely the collection of such data via an application or a specific insurance product. The laws do not prohibit plans from collecting race and ethnicity data as part of a disease management program or on a voluntary basis, as long as the collection is not part of the application process.

#### Collection of Data on Primary Language

More than half of the enrollees (58%) are in plans that indicated they also collect data on the primary language of their enrollees. Individuals enrolled in Medicaid or Medicare were more likely to be in plans that collect primary language than those enrolled in Commercial plans, 89% vs 53% respectively (see Figure 7). Regardless, Commercial plans are offering language access services at the same rates as Medicare and Medicaid plans. Almost all enrollees (99.8%) represented in our survey are in health insurance plans that offer language access services.

The primary reasons why plans indicated they collect information on language of enrollees include to:

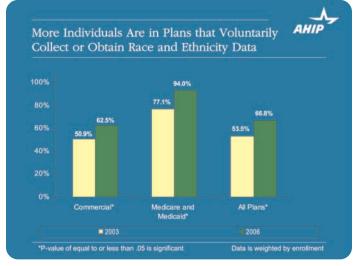
- determine the need for translation of materials
- determine the need for interpreter services
- ensure the network of providers speaking enrollees' language is adequate



**Figure 7**Enrollees in Health Insurance Plans that Collect Data on Primary Language

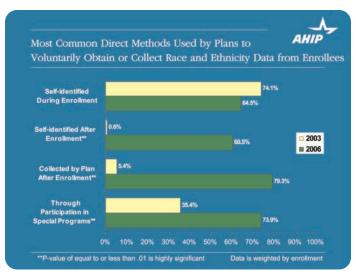
#### Comparison Between 2003 and 2006 Surveys

Comparing the responses to questions asked in both 2003 and 2006 indicates that several important changes occurred during the three year period. Of primary interest is that all of the plan types increased the collection of race and ethnicity data for their enrollees. In 2006, 67% of enrollees were covered by health insurance plans that collected race and ethnicity data, compared to 54% in 2003. The largest increases were seen in Medicaid and Medicare plans with 94% of enrollees covered by plans that collect or obtain race and ethnicity data (see Figure 8). According to the 2006 AHIP-RWJF survey, a total of 58.2 million enrollees represented by our survey are covered by health insurance plans that collect or obtain data on their race and ethnicity. In addition, significantly more enrollees are in Medicare and Medicaid plans that indicated they collect or obtain data on primary language of their enrollees (89.4% in 2006 vs. 74.3% in 2003).



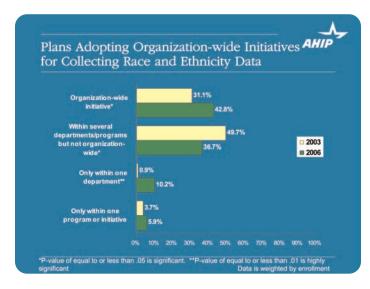
**Figure 8**Enrollees in Plans that Collect or Obtain Race and Ethnicity Data, by Year

Another change between the 2003 and 2006 surveys was that more enrollees, in 2006, were providing information about their race and ethnic background after enrollment (e.g., satisfaction surveys, special programs) (see Figure 9). This trend may reflect several changes in the marketplace, such as a growing interest and sophistication of plans regarding the importance of collecting race and ethnicity data; and a better understanding among enrollees of the importance of providing this information for quality improvement efforts and targeted interventions that meet their cultural and linguistic needs.



**Figure 9**Methods Used by Plan to Obtain or Collect Race and Ethnicity Data Directly from Enrollees.

In 2003, the most common data collection practice of health insurance plans occurred within several departments or programs but not organization-wide. The 2006 survey revealed a trend toward integrating data collection practices as part of a system-wide effort. Now, the typical practice by health insurance plans is through organization-wide efforts (see Figure 10).



**Figure 10**Organization-wide Efforts to Collect Race and Ethnicity Data

#### **COLLECTION OF DATA ON PHYSICIANS/CLINICIANS**

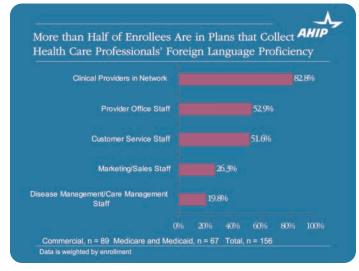
#### Collection of Physician/Clinician Race, Ethnicity, and Primary Language Data

Forty-four percent (69 of 156) of responding plans indicated that they collect race and ethnicity data on any or all of the physicians/clinicians within their networks, with rates much higher in Medicaid (72%) than Commercial (32%) and Medicare (29%) plans.

Among those plans that collect this information on their physicians, 62% of enrollees have access to race and ethnicity data on their physicians/clinicians. Data shows that Commercial plans frequently provide this information to their enrollees in the absence of federal regulations that Medicare and Medicaid plans are subject to. Furthermore, more health insurance plans are making race and ethnicity data about their providers available to their enrollees (65.8% in 2006 vs. 29.3% in 2003). This increase was seen for each product.

Overall, 83% of enrollees are in plans that collect information on provider's fluency in foreign languages. More than half of enrollees are in plans that collect this information from provider office staffs (53%) and from plan customer service staffs (52%) (see Figure 11). Enrollees have access to this information through several sources. These include:

- provider directories (80%)
- ▶ plan websites (68%)
- communication with customer service staff (40%)
- member materials, such as member handbooks, letters, printed brochures, and newsletters (31%)



**Figure 11**Percentage of Enrollees in Plans that Collect Information on Health Care Professionals' Foreign Language Proficiency

#### CONCLUSION

Results from the 2006 AHIP-RWJF survey indicate that the trend is moving toward increased collection of race and ethnicity data from enrollees. Furthermore, plans are using this information to examine issues of health disparities among their enrollees and to improve overall quality. This information is much more promising than a study in 2002 that indicated that many health plans did not collect this information,<sup>6</sup> and another study that indicated Medicaid agencies were collecting race and ethnicity data but not using it to conduct research on health disparities in the Medicaid population.<sup>12</sup>

It was also encouraging to note the high proportion of health insurance plans that are collecting language information on their enrollees and offering language assistance services. This is particularly significant given recent research indicating that the use of language assistance can improve care.<sup>13</sup> One project that reviewed the experiences of 14 health plans that have been at the forefront of linguistic competence efforts suggests that health plans are engaged in several activities, including: developing a language-assistance plan, collecting and using language data, educating physicians and holding them accountable, recognizing language assistance as an integral part of quality, and negotiating with purchasers.<sup>14</sup>

#### Research Highlights:

- Between 2003 and 2006, health insurance plans have made significant progress in collecting race and ethnicity data for quality improvement and to identify differences in treatment, medication adherence, and prevalence of enrollees' chronic conditions that can be improved and managed through preventive and educational measures.
- Plans are using data on race, ethnicity, and primary language to enhance culturally and linguistically appropriate programs for all enrollees.
- ▶ Opportunities exist to encourage commercial plans to collect data on the primary language of their enrollees, and for all plans to collect data on race/ethnicity and foreign language fluency of providers.

As the demand grows to address the disparity gap, the use of race and ethnicity information will become more important. Standards will need to be developed for collecting and categorizing this information in health care settings. <sup>6,15,16,17,18</sup> One group of researchers in health maintenance organization settings has provided recommendations for categorizing race and ethnicity. <sup>6</sup> Others have

called on HHS to develop comprehensive guidelines encouraging race and ethnicity data collection as part of quality improvement and to reduce health disparities.<sup>19</sup>

Health insurance plans can make a valuable contribution toward reducing racial and ethnic disparities in health by collecting and using these data for quality improvement. Collecting race and ethnicity data is a first step. However, as more health plans collect this information, we need to start developing and sharing best practices for how this information can be used to reduce disparities in health and in the health care setting. There is some data suggesting successful efforts,<sup>20</sup> and other potentially successful interventions are currently being explored.<sup>21</sup> Moreover, we also need to identify how to best reduce consumer concerns about collecting and using race and ethnicity information.

#### Recommendations:

- Develop comprehensive standards on how best to collect race, ethnicity, and primary language data from enrollees and providers.
- ▶ Ensure uniformity of data categories for measuring progress in reducing disparities across the health care sector.
- ▶ Expand cultural competency training of practicing physicians and as part of a medical school curriculum
- ▶ Conduct additional research and focus on identifying best practices to determine effective strategies and interventions to close the gaps in care.

Education and outreach can demonstrate the power of data to improve health care and health status of diverse populations. AHIP has developed tools for health insurance plans, providers and health care organizations concerned with addressing disparities. As part of its *Addressing Disparities in Health Initiative*, AHIP sponsored regional workshops in 2005 for health insurance plans and developed a data collection toolkit, *Data as Building Blocks for Change*, to increase the rationale for, and importance of collecting data on race, ethnicity, and primary language. AHIP has also launched a crosscultural continuing medical education module for physicians and an online communications compendium of resources for creating a culture of cultural proficiency within organizations, *Communications Resources to Close the Gap*. It is currently establishing a clearinghouse of success stories. These tools provide valuable resources for organizational change.

The results of the 2006 survey conducted by America's Health Insurance Plans and the Robert Wood Johnson Foundation provide some optimism about the future direction in addressing health care disparities among racial and ethnic populations. Health insurance plans have increased their awareness of the importance of collecting data on race, ethnicity, and primary language of their enrollees in identifying, measuring, and reducing differences in care. As the development of effective, evidence-based interventions and culturally and linguistically appropriate programs continues to evolve, health insurance plans are key players in reducing inequities in care and improving health care quality for all Americans.

#### **METHODOLOGY**

The sample for this survey was primarily drawn from the 2005 Atlantic Information Services (AIS) Directory, and supplemented with information from the InterStudy Competitive Edge, Part I: Managed Care Directory, Version 13.2 and the CMS data set. Plans were excluded if they were: leased networks; no longer in business; merged with other entities; subsidiary or regional branch of a parent company; or had no valid contact information. Health insurance plans were selected through a stratified random sample segmented by the type of product (Commercial, Medicaid, and Medicare).

A 42-question web-based survey was developed to meet the objectives of this project. A core set of questions were consistent with the 2003 survey to allow for comparison. A small number of questions were added or deleted from the 2003 survey version to capture information on marketplace or organizational factors, as well as new issues identified since 2003 that influence data collection.

Figure 2 shows the percentage of enrollment in the health plans that collected race and ethnicity data in any given year between 1980 and 2006 as compared to the total enrollment in the plans that collected race and ethnicity data in 2006 (based on the 2006 enrollment numbers).

Note: The precision of such representation is somewhat limited by the changes in enrollment experienced over the time. This graph is based on the self-reported data, captured by question 27, on the onset of collecting race and ethnicity data by health plans.

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America's Health Insurance Plans

601 Pennsylvania Ave., NW South Building Suite Five Hundred Washington, D.C. 20004

202.778.3200 www.ahip.org